Data Release Review Committee

January Meeting Notes

The following documents the meeting convened on 1/8/2025:

Committee Member Attendees:	CIVHC Staff Attendees:	
☒ Ako Quammie (Contexture)	☒ Kelsey Foland	☐ Liz Mooney
☒ Andy Woster (CCMCN)	☒ Abby Fehler	☒ Lucía Sanders
☒ Beth Martin (HCPF)	☒ Amanda Kim	☒ Maggie Mueller
☐ Caleb Wright (Elevance Health)	☒ Danielle Evergreen	☒ Martha Meyer
☒ Chris McDowell (Valley Health Alliance)	☒ Darcy Holladay Ford	☐ Mason Thaxton
☒ Essey Yirdaw (Colorado Hospital Association)	☐ Hannah Witting	☒ Pete Sheehan
☐ Jesse Villines (Craig Hospital)	☒ Jacque Lewis	☐ Sauntice Washington
☐ Megan Denham (Georgia Tech)	☐ John Francis (counsel)	☐ Twanisha Parnell
☒ Nathan Wilkes (Headstorms, Inc.)	☐ Ken Holtschlag	☒ Isaac Nwi-Mozu
☐ Sheri Herner (Kaiser Permanete)	☐ Kristin Paulson	☐

Agenda

10:30 AM	25.13
Requesting Organization:	University of Colorado, Anschutz Medical Campus, School of Medicine (CU)
Project Title:	Healthcare Resource Utilization in Patients with Stiff Person Spectrum Disorder
11:00 AM	**25.91**
Requesting Organization:	Center for Public Health Innovation (CPHI)
Project Title:	Colorado Sickle Cell Data Collection Program
11:30 AM	**25.26**
Requesting Organization:	University of Colorado, Anschutz Medical Campus, School of Medicine (CU)
Project Title:	What is emergent enough? Quantifying life-threatening pregnancy complications for a post-Dobbs world

Data Release Review Committee

January Meeting Notes

12:00 PM	25.107.10
Requesting Organization:	Colorado Department of Public Health and Environment – Primary Care Office (CDPHE)
Project Title:	State Rational Services Areas Model Innovation

Data Release Review Committee

January Meeting Notes

10:30 AM	25.13
Extract Type:	Limited
Requesting Organization:	University of Colorado, Anschutz Medical Campus, School of Medicine (CU)
Project Title:	Healthcare Resource Utilization in Patients with Stiff Person Spectrum Disorder
CIVHC Presenter:	Lucía Sanders, Key Account Manager
Project Presenter(s):	Amanda Piquet, MD Eric Gutierrez, MPH Kavita Nair, Co-Investigator Mallory Lowe, Co-Investigator Eric Engebretson, Project Manager

Requested Protected Health Information (PHI):		
Requested	Approved	Data Element
☒	☒	**Member 5-Digit Zip Code**
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Data Release Review Committee

January Meeting Notes

Committee Discussion and Questions

- Lucía provides brief overview of request
- Project team joins call and shares further details, noting this is a follow-up to a recent publication (publication materials shared in presentation are available here)
- Andy: curious with the small sample size, curious if Payers were checked in the chart reviews—that should give insight to the match rate for the CO APCD pull
    - Dr. Piquet: we can look at the current Payer, but retrospectively we cannot always see who the insurer was at time of diagnosis
    - Kavita Nair: CO APCD data is so useful because this is such a rare disorder. Patients are often passed around, so it's very valuable to have the full journey and see more information about handoffs, which helps eliminate disparities
- Project team drops from call and Kelsey requests further questions from the Committee
- No further questions from the Committee; no objections raised by the Committee

DRRC Recommendation

Does the DRRC recommend this project for production?	☒ **Yes**	☐ No
First Motion to Recommend:	Chris McDowell (Valley Health Alliance	
Second Motion to Recommend:	Nathan Wilkes (Headstorms, Inc.)	
Production condition(s):	No conditions Add explanation here if there are production conditions.	
Are there objections to this project's production? *Production is not recommended if three (3) or more Committee members object.*	☐ Yes	☒ **No**
DRRC Objector:	Basis for Objection:	

Data Release Review Committee

January Meeting Notes

11:00 AM	25.91
Extract Type:	Identifiable
Requesting Organization:	Center for Public Health Innovation (CPHI)
Project Title:	Colorado Sickle Cell Data Collection Program
CIVHC Presenter:	Lucía Sanders, Key Account Manager
Project Presenter(s):	Joshua Miller, Senior Public Health Analyst Rhonda West, Associate Public Health Analyst

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Committee Discussion and Questions

- Lucía provides brief overview of request
- Beth: having some technical difficulties accessing files—is there an IRB Approval in place?
    - Lucía: there is an IRB Approval in place from COMIRB, paired with an independent review process
- Essey: Google indicates the population of roughly 10%-- is this for the pediatric population?
    - Lucía: we working solely off the diagnosis codes and identifying everyone in the APCD with that diagnosis regardless of age
    - Essey: is there a plan to capture the uninsured? Noting that these are often marginalized groups already, there is a cross-section there that would be meaningful to study
    - Lucía: not personally equipped to answer that question, but that's a great one for the requestor group to talk about further
- Andy: not familiar with this nonprofit group's work or infrastructure. Is that captured in the Data Management Plan to ensure the security needs are in place?
    - Kelsey: around this time in the project journey, the CIVHC representative will send the Data Management Plans to Compliance for review and Compliance can request further detail when needed. The DMP for this request was approved this week
    - Andy: does this organization have the internal file structure, or will this all be flat feature?
    - Lucía: they will be working with the Microsoft Certified Data Center program
- Ako: within the DRA, the multi-year selection rolls up to 2026, which we don't have yet. But it appears that 2024 is not selected?
    - Lucía: 2024 was not selected here because the first data extract they receive will be running through the entire year of 2023. Runout for 2024 will not be in place until May, so next February will see them receiving the full year of 2024 data, followed by an extract every three years
- Project team joins call and shares further details, noting the role opioids are playing
- Nathan: a lot of the outcomes being looked at are based on geographic distribution of services. Employer was mentioned as a focus area as well; can you talk a little more about stratification of services based on income and social determinants of health?

    - Joshua Miller: the manuscripts on the Social Vulnerability Index were included, which has been a helpful angle. The CDC doesn't require all angles be reported to them, but CPHI has engaged in many side projects looking at things like the transition from pediatric to adult care. There are goals to stratify by employment variables, with the next CO publication focusing on employer stratification. Current reporting has been narrowed to CDD requirements, but receiving a CO APCD data set will allow us to look at even more buckets, including the integration of quality of life into the data

    - Nathan: will you be looking at the difference between coverage?

    - Joshua Miller: absolutely, there is a significant breakout between Commercial and Medicaid coverage that we will be looking into further

- Essey: since there's no self-pay option through the APCD, will you factor in the loss of employment status resulting in a move to Medicaid? Does there need to be a complementary data set

    - Joshua Miller: that is definitely a limitation to this, but we are very eager to have access to this data for the first time. Provider data from Health Data Compass had to be redacted entirely. CIVHC has shared some recommendations to reach out to the Colorado Hospital Association to help fill in some gaps, which will certainly be an upcoming goal. Now that Essey is an official contact, this will be fantastic to explore sooner rather than later

- Ako: the presentation mentioned a million-dollar legislative fund for research on this disease. Do you know if that award has been made? And are there any geographic limitations for that given the regional constraints?

    - Joshua Miller: applications for funding are opening in January, so the Denver CBO has already begun that work. Colorado Springs also has a CBO, which might be some competition, but we are anticipating funding to come through early this year. The geographic limitations of CBO regions are on our radar, but more discussions are upcoming to determine further overlap

- Project team drops from call and Kelsey requests further questions from the Committee

- Ako: the presentation noted that they received data from Health Data Compass, who receives data from the CO APCD. Did we know that

    - Lucía: we were aware of this. HDC no longer has a contract with CIVHC. HDC data is limited with the sickle cell data inclusion, we have looked into those connection points

    - Ako notes the underserved communities are generally in rural areas, with the focus of this study likely focusing on the I-25 corridor given the condensed populations in those city centers. It would be fantastic to see more of a state-wide effort in future iterations

DRRC Recommendation

Does the DRRC recommend this project for production?	☒ **Yes**	☐ No
First Motion to Recommend:	Ako Quammie (Contexture)	
Second Motion to Recommend:	Essey Yirdaw (Colorado Hospital Association)	
Production condition(s):	No conditions Add explanation here if there are production conditions.	
Are there objections to this project's production? *Production is not recommended if three (3) or more Committee members object.*	☐ Yes	☒ **No**
DRRC Objector:	Basis for Objection:	

Data Release Review Committee

January Meeting Notes

CIVHC
CENTER FOR IMPROVING VALUE IN HEALTH CARE

11:30 AM	25.26
Extract Type:	Limited
Requesting Organization:	University of Colorado, Anschutz Medical Campus, School of Medicine (CU)
Project Title:	What is emergent enough? Quantifying life-threatening pregnancy complications for a post-Dobbs world
CIVHC Presenter:	Lucía Sanders, Key Account Manager
Project Presenter(s):	Nancy Fang, MD MS, Assistant Professor

Requested Protected Health Information (PHI):		
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Committee Discussion and Questions

- Lucía provides brief overview of request
- Project requestor joins call and shares further details
- Nathan: curious about the comparisons to VA—demographics are a little different, what are you doing to normalize those differences?
    - Dr. Fang: the APCD data definitely reflect different populations. We will compare on race/ethnicity to the best of our ability and adjust for personal variables such as age. While it won't be a head-to-head match for VA, there will be clear differences in how morbidity and mortality show up in the data for a state with such different policies
- Project requestor drops from call and Kelsey requests further questions from the Committee
- Ako: loved getting to see the previous materials from the past request, that was very nice
- Andy: this is a little zoomed-out, but in terms of the information they are receiving, are they receiving out-of-state resident claims for services rendered here in Colorado?
    - Kelsey: no, they are not
    - Martha: it would be great to have that information in this case, but we don't
    - Kelsey: we have some payers who have asked if they could submit data for out of state residents, but the answer so far is no due to the lack of enforcement mechanisms

DRRC Recommendation

Does the DRRC recommend this project for production?	☒ **Yes**	☐ No
First Motion to Recommend:	Nathan Wilkes (Headstorms, Inc.)	
Second Motion to Recommend:	Andy Woster (CCMCN)	
Production condition(s):	No conditions Add explanation here if there are production conditions.	
Are there objections to this project's production? *Production is not recommended if three (3) or more Committee members object.*	☐ Yes	☒ **No**
DRRC Objector:	Basis for Objection:	

Data Release Review Committee

January Meeting Notes

12:00 PM	25.107.10
Extract Type:	Identifiable
Requesting Organization:	Colorado Department of Public Health and Environment – Primary Care Office (CDPHE)
Project Title:	State Rational Services Areas Model Innovation
CIVHC Presenter:	Amanda Kim, Director of Colorado State Initiatives
Project Presenter(s):	Tamara Davis, PCO Program Manager Steve Holloway, PCO Director

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Committee Discussion and Questions

- Amanda provides brief overview of request
- Beth: while reading through the request and reviewing the previous request materials. Feeling a little nervous about the request, and after checking the legislation, this does not seem like it meets minimum necessary
    - Amanda: this level of identifiable elements should absolutely elicit additional scrutiny. There have been some internal discussions about public health exceptions as it pertains to CDPHE specifically. This is a great arena for this discussion, so let's flag any concerns or suggestions to take advantage of the time we have them
    - Beth: we need to find areas of care to see where behavioral health is under-served and where primary locations are. But there's not anything in the Bill about the diagnosis codes for behavioral health. Sharing data between HCPF and CDPHE entails a separate process because CDPHE is not a Business Associate. This will be a tricky conversation to have with HCPF Legal
    - Ako: relating to the Public Health exception, that relates to the national level. CDPHE is a number of departments all sitting under one umbrella, but even within the departments each group requires MOUs
    - Amanda: if at all possible, let's flag as many of these concerns for them directly to avoid anything getting lost in the handoffs from Amanda to the project team
- Project team joins call and shares further details
- Beth: this is really cool work that has been happening, excited to send HCPF people over to see the maps. However, definitely nervous with the request for all diagnostic codes for all Coloradans, unsure how we could justify such a big request. There are a lot of pieces that neatly play into the request and the underlying legislation, but the external social determinants of health require matching to exact name and DOB, etc. Could you explain a little further?
    - Steve Holloway: prefacing with security standards, the Microsoft platform scores higher than the state OMB level. All access is managed through certification levels, and the data is only held for the time it takes to perform the analysis. One possibility is to purge all PII and PHI once the matching is done to ensure nothing is held in the system
    - Steve: regarding the specific question, we fully acknowledge how highly sensitive this data is. To perform the level of analysis we intend, we can't find any other option. The public health significant is substantial—over 100 service areas in Colorado currently receive a brief analysis, but without any understanding of subsets. Colorado is such a unique state, not experiencing segregation across cities in the same way coastal cities. So many marginalized people are hidden in larger populations, and seeing birth impacts would benefit tremendously. We do feel that this work is explicitly covered in the Bill

- Beth: in terms of the broad level of data, is there another path? If you're determining the type of provider, maybe we don't deliver every detail associated with the care visit? Looking at the original legislation that kicked off this work, it talks about behavioral care, but it doesn't specify that the diagnosis itself needs to be known in order to identify the connection points. Recognizing the complexity of peri-natal data, is there a way you could share diagnosis code and procedure code lists for the data pull to start with? Is there anything we could do to scale down the data delivered without losing the connection points between Location A and Location B and why? Anything that lets us protect more data of people at risk

- Amanda: for the first ask, there was a list of codes so we were only looking at primary care code. This second request is expanding to per-natal, which we were looking at a code list for. Is that still the case?

    - Steve: we have been working on a list of proxy codes that let us know which claims are behavioral health without touching SUD. We are interested in ambulatory care, not so much inpatient care. Summarizing that a patient had one or more of the codes would still function, albeit more work on the side of the developers to build the extract

    - Beth: filtering by a code list would make this so much easier, but if it's financially prohibitive to redo the coding work the request would have to go to HCPF Legal. Documenting the recoding on the CDPHE side would give us a lot more ground to move forward

    - Steve: perhaps a two-step system could also be created to build in non-reversible identifiers, only after which would the diagnostic codes come into play. That would allow us to blind ourselves to the connection of PHI to diagnoses, but still move forward with analysis

- Ako: on the other side of geographic mapping, has there been consideration for Payer programs in which the insurance company restricts the use of certain groups and/or coverage? From your mapping exercise with distance traveled, there's obviously a lot more information that would be available through this data set. Do you have the ability to see which plan a patient is on and how that impacts their provider availability which is why they're traveling?

    - Steve: what this analysis does is represent what is, not what should be. Our charge is to identify what should be and then incentivize migration to that ideal state. We have some strategies to shed light on this challenge, and we're hoping this study reveals network inadequacy. If groups appear to be bypassing the nearest source of care, the public health question is: why is this happening? This project is compelling academically, but we are truly trying to understand barriers to care and why groups are impacted. The DOI has been keenly interested in what this research might discover about true network adequacy versus what insurance carriers are stating their network adequacy is

- Nathan: as part of the new data requested here for linkage, can you elaborate on what you will be pulling in from the Melissa database?
    - Steve: the database has hundreds of fields on every individual in the country. We are interested in race/ethnicity, X, income level, minor children in the household, and number of adults in the household. We have built a social health index to operate within Colorado and identify service areas and their corresponding levels of care
- Project team drops from call and Kelsey requests further questions from the Committee
- Beth: really okay with stratifying the release of data. If we can identify which fields can be sent out that clearly meet minimum necessary right now (i.e. person and location information), we can send that release so their projects can get started, we can work out some options for releasing the diagnostic data
    - Ako: for hospitals we have DRG codes, Ambulatory has their own code sets. If those categories can be placed instead of actual code sets, we can get around identifiable information in State systems. Some of those elements are subject to CORA—it's worth finding a way to get the range that they need without all the requested information
- With three objections from the Committee, this request will need to be adjusted before it can be reconsidered for Production. Beth is available to meet with the CIVHC team to assist finding a better way to achieve these project goals

DRRC Recommendation

Does the DRRC recommend this project for production?	☐ Yes	☒ **No**
First Motion to Recommend:		
Second Motion to Recommend:		
Production condition(s):	Choose an item. Add explanation here if there are production conditions.	

Are there objections to this project's production? *Production is not recommended if three (3) or more Committee members object.*	☒ **Yes**	☐ No
DRRC Objector:	Basis for Objection:	
Beth Martin (HCPF)	The request as it stands does not meet minimum necessary	
Ako Quammie (Contexture)	Ako seconds the above concern	
Nathan Wilkes (Headstorms, Inc.)	Nathan thirds the above objection	